NAACCR

I.T. Worked for Me: In"FUN"matics in the Cancer Registry

RONDA BROOME, CTR LISA LANDVOGT, CTR KELLY MERRIMAN, CTR

7/13/23

NAACCR

Q&A

Please submit all questions concerning the webinar content through the Q&A panel.

If you have participants watching this webinar at your site, please collect their names and emails.

We will be distributing a Q&A document in about one week. This document will fully answer questions asked during the webinar and will contain any corrections that we may discover after the webinar.



NAACCR

Guest Presenter

- Lisa Landvogt, BA, CTR
 - Director of Cancer Data and Accreditation, Henry Ford Health
- · Kelly Merriman, MPH, PhD, CTR
 - Director, Tumor Registry, MD Anderson
- Ronda Broome, MSHMI, MS CTR
 - Associate Director of Clinical Abstraction, Syapse

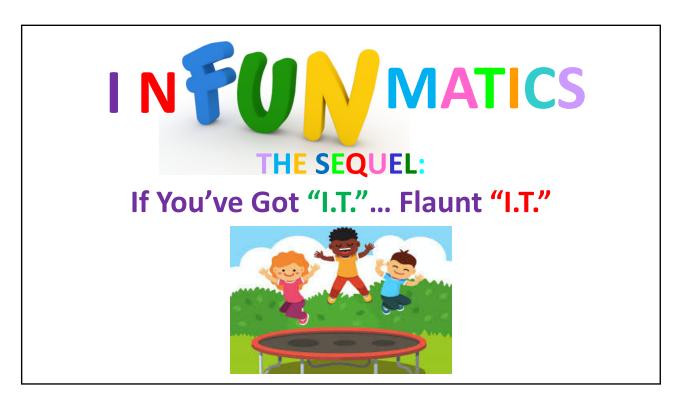
North American Association of Central Cancer Registries (NAACCR) Webinar Series July 13, 2023

Featuring: Lisa Landvogt, Kelly Merriman, and Ronda Broome

MDAnderson Cancer Center

Making Cancer History®

Syapse...



Takin' Care of Business

- Disclosure on behalf of the three guest presenters
 - None of us have any relevant financial or non-financial relationship in products or services we may describe, review, evaluate or compare during this presentation.



WORTHLESS STATEMENT

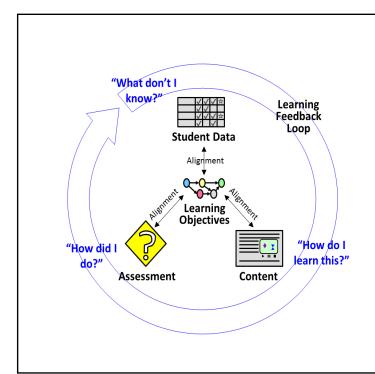
We come before you, to stand behind you.

To tell you something we know nothing about.

Next Thursday, the day after Friday, there will be a ladies meeting for men only. Please wear your best clothes if you have

And if you can come, please stay home. Admission is free, or you can pay at the door

We'll give you a seat, so you can sit on the floor



Webinar Learning Objectives

Describe how informatics can be leveraged by cancer registrars to capture essential cancer data

Describe the mixture of technology with data and utilizing the outcome to share relevant and valuable data analysis

Describe how the creative use of information technology (I.T.) can elevate and sustain the role of the certified tumor registrar (C.T.R.) into a level of scientific contributions to timely and quality-based cancer data collection and analysis for real world data use, while enjoying your career and having fun

Inquiring Minds Want To Know

- Poll Questions (one at a time please)
 - 1. How would you classify your current status?
 - 1. Current Certified Tumor Registrar (CTR)
 - 2. CTR Eligible
 - 3. Other/Interested in the CTR profession but not yet eligible (still in school, exploring, undecided)
 - 2. Are you currently part or full-time employed as a CTR or CTR eligible, if yes what type of facility employs you?
 - 1. Hospital/Health System/Clinic
 - 2. Outsourcing Cancer Registry Vendor (company or self employed)
 - 3. Cancer Registry Data Software Vendor
 - 4. Other/State/Central Registry/SEER/NIH/CDC etc.
 - 3. Cancer Registry/Data Experience How much experience do you have that you would list on a resume?
 - None
 - 2. 2 years or less
 - 3. More than 2 years and less than 5 years
 - 4. More than 5 year and less than 10 years
 - 5. More than 10 years and less than 20 years
 - 6. More than 20 years





Inquiring Minds Want To Know, Part II

- Poll Questions (one at a time please)
 - 1. Do you currently work remotely?
 - 1. No
 - 2. Yes
 - 3. Hybrid format
- ${\it 2.} \quad {\it Are you interested in career development/growth opportunity as a CTR or soon to be CTR?}\\$
- 1. Yes, definitely
- 2. No, not really, I like what I do
- 3. Pretend you work full-time (multiply your hourly salary by 2080, that is your annual salary, select your category
- 1. Less than \$40,000
- 2. \$40,001 through \$52,000
- 3. \$52,001 through \$64,000
- 4. \$64,001 through \$75,000
- 5. More than \$75,001



Evolution to Revolution - Fast Forward

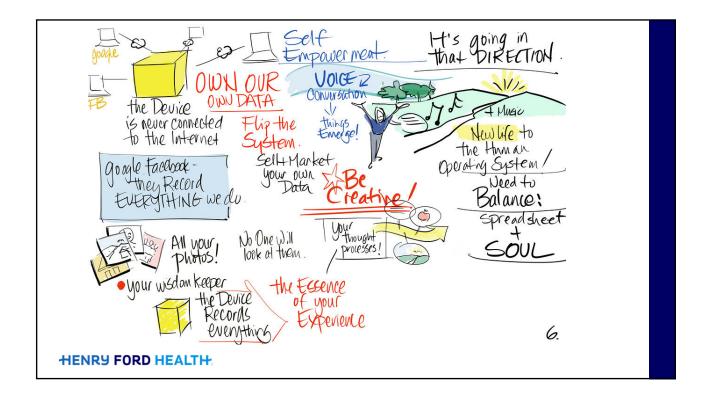


HENRY FORD HEALTH.

We Are On Our Own Moonshot Mission

- CTR's are more like EMT's (Substitute the acronym from Emergency Medical Technician to Expert Multi-Tasker)
 - -It is a true talent and that needs to be recognized as a major component of a CTR's ability to flow with the many changes, responsibilities, and implementation of ensuring all the T's are crossed and the i's are dotted.
- Think about the term informatics and how it relates to the responsibilities of a CTR in 2023 (STOP looking back!)
- The worst statement an employee can utter is "but, that is how we always did it."





Informatics Defined

- Cancer Informatics is the **intersection** of information science, computer science, medical oncology, communication, and health care.
- It deals with the **resources**, **devices**, **and methods required to optimize** the acquisition, storage, retrieval, and use of information in cancer.
- Applied cancer informatics turns clinical data into meaningful and useful information to improve processes and outcomes in patient-focused and evidence-based cancer care. Informally, cancer informatics supplies the right information, to the right people, in the right format at the right time.



Four Pillars of Cancer Informatics

- Informatics Theory: Systems, Information Flow, and Knowledge Concepts
- Technology: Hardware and Software Tools in Support of Creating Data to Model Outcomes
- Biological Sciences: Life Science Disciplines, including Scientific Inquiry Principles Cancer Informatics Resources
- Social Perspectives: Human-centered Interactions in an Organizational or Cultural Context





PILLARS

NOT

PILLOWS



Moonshot Mission CTR v23 Details

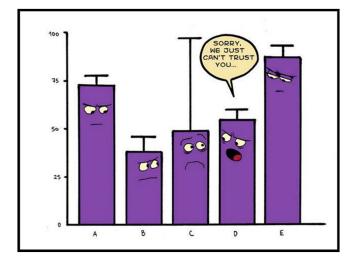
- Case Finding
- Abstracting
- Follow-up
- Quality Control/Peer Review
- Data Operations/Requests/Reports
- Staffing Management
- Accreditation(s)

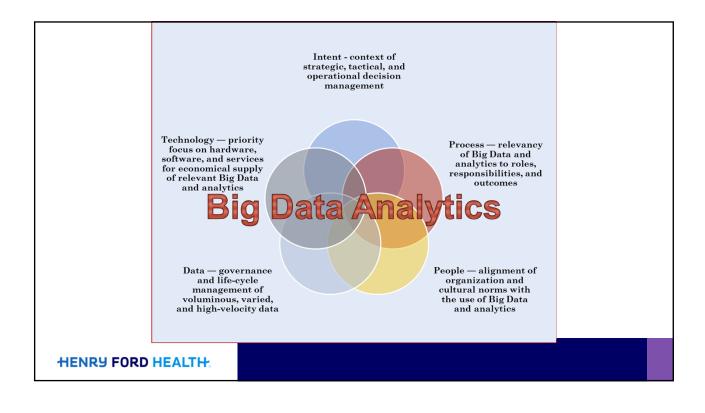


Cancer Registry Data MUST be the source of truth

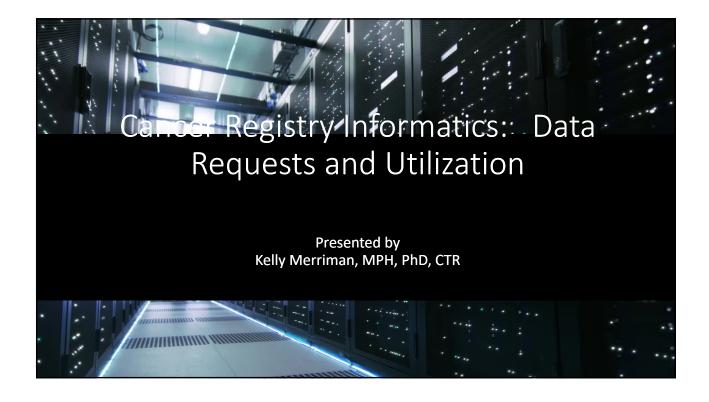
HENRY FORD HEALTH.

Trust Your Instincts, Validate Your Hunches... The Truth is in the Data









SPECIAL SERIES: CANCER CLASSIFICATION SYSTEMS

Check for updates

Evolution of the Cancer Registrar in the Era of Informatics

articles

Kelly W. Merriman, MPH, PhD, CTR¹; Ronda G. Broome, MS, MSHMI, CTR²; Giordana De Las Pozas, MD¹; Lisa D. Landvogt, BA, CTR³; Ying Qi, MS, CTR⁴; and Judith Keating, CTR⁵

Darrac

The cancer registrar reports accurate, complete, and timely abstracted cancer data to various healthcare agencies. The data are used for understanding the incidence of cancer, evaluating the effectiveness of public health efforts in the prevention of new cases and improving patient care outcomes and survival. There are increasing demands placed on registrars for additional data points with real-time submission to reporting agencies. To that end, registrars are increasing the use of informatics to meet the demand. The purpose of this article is the role of the registrar in the collection and reporting of critical cancer data and how registrars are currently using informatics to enhance their work. This article describes how informatics can be leveraged in the future and how registrars play a vital role in meeting the increasing demands placed on them to provide timely, meaningful, and accurate data for the cancer community.

JCO Clin Cancer Inform 5:272-278. © 2021 by American Society of Clinical Oncology

Value of Cancer Registry Data

- Our data captures a complete summary of a cancer patient's history, diagnosis, treatment and vital status
- Often considered the gold standard for cancer diagnosis and stage
- Vital status and Date of Last Contact/Death Date are critical data elements for survival analyses
- As a result our data is in high demand from a research perspective

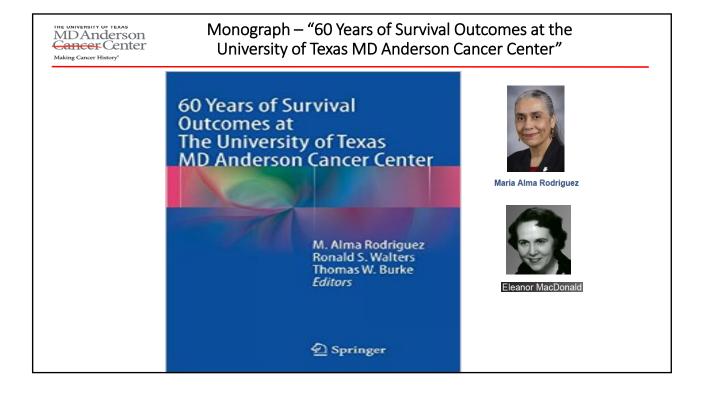


Data Requests

- We are often approached for data requests and/or presenting data to the Cancer Committee
- Requestor often does not know what they are asking or what is available
- Presents opportunities for collaboration



https://unsplash.com/s/photos/collaboration



Different Types of Data Requests

- Operational Requests involve questions about the operations of the hospital/business
- Generally at the aggregate level
- Examples:
 - How many new cancer patients presented at your facility last year
 - Of those, how many of these patients had treatment at your facility
 - Of those, how many were admitted into the hospital
- Quality Improvement Improving a process or activity within your facility
- Preparatory to Research may be conducted prior to or without IRB approval
- Research Systematic investigation designed to develop or contribute to generalizable knowledge



Handling of Data Requests Most data requests using Cancer Registry data are retrospective in nature Since retrospective chart reviews generally involve a large number of records thus informed consent and authorization are not required The investigator must obtain a waiver of authorization from the IRB, so still ask for IRB Often times just Summary level data (Counts) are needed Data does not contain any elements of PHI Represents totals of de-identified patient data Leverage commercialized cancer registry systems/reports



Tumor Registry Usage for Research

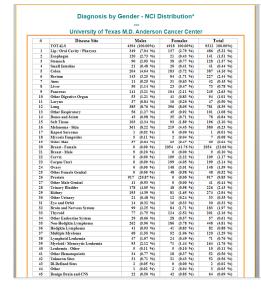
- Identify a cancer cohort of interest
- Case count for research grants
- Confirmed tumor disease and treatment information for a specific patient population or ingestion to a database/system
- Follow-Up/Survival information for patients in a departmental database or studies
- Matching for study populations



Data Request Examples for Ad-hoc Queries

- · What are the top Histologies that metastasize to the brain
- Total number of cases of adenoid cystic carcinoma of the vulva we have treated (3 cases)
- · Identify synchronous and multiple primary cancer patients
- Provide the top 5 cancers for various cities, states, countries over the last 5 years (Development Office, External Communications)
- Total number of breast cancer patients and who are pregnant (askMDAnderson)
- · Match lung cancer cases with control group of bladder cancer, matching upon dx age, sex, and race
- Identify second primaries from breast cancer patients, now presenting with lung cancer with exposure to XRT controlling for timing of exposure

Utilizing Commercialized Tumor Registry Reports



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Diagnosis by Gender - NCI Summary 3 Distribution - Business Rules

Percentages Are:

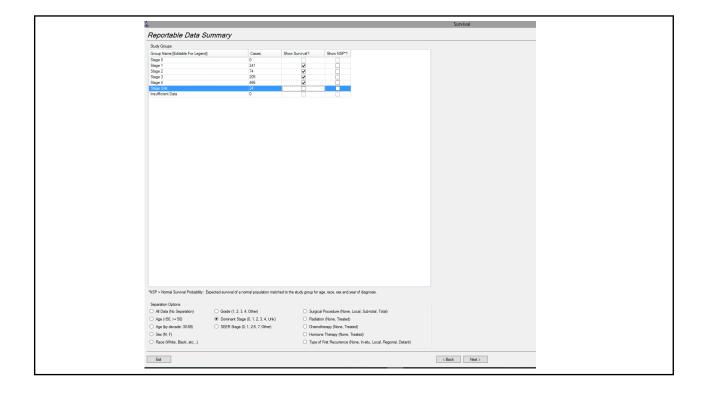
This report provides total counts of diagnoses for each gender grouped according to standards defined in the National Concern Entertine Commentary - Interim Revision. June 2005. updated Concern Enter Summaries - Interim Revision. June 2005. updated Concern Content Service - Concerns - Con
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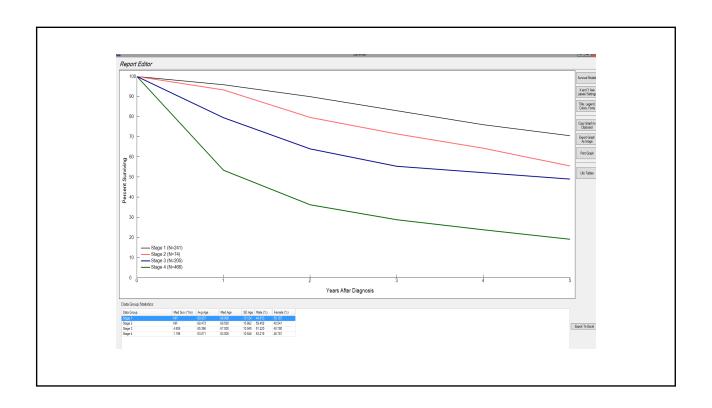
Oncolog Demo for Survival Analyses

• From your Tumor Registry list 5-year Survival Rates for the most recent available ANALYTIC CASES treated at your institution. In the fifth column, enter the time frame of analysis (e.g. 2014-2018)

	Stage 1	Stage 2	Stage 3	Stage 4	Time Frame
Breast	97.0	91.4	78.9	45.5	2014 - 2018
Colon	91.2	90.7	82.9	31.4	2014 - 2018
Lung	73.0	55.1	37.4	14.0	2014 - 2018
Prostate	93.0	95.4	91.4	68.2	2014 - 2018









Data Analytics from a Registrar's Perspective

- Need a basic understanding of statistics and epidemiology to understand the cancer literature
- A cancer registrar's job is to provide the data for our researchers and our administrators, not to do the statistics for them
- Though, the registrar may often perform some basic summary level data for data requestors conducting research or operational purposes

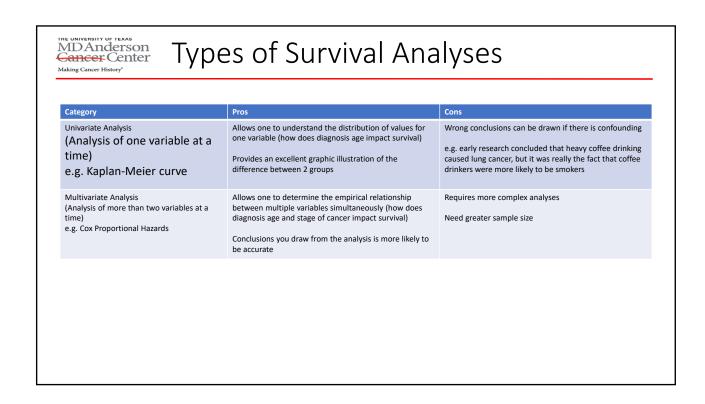


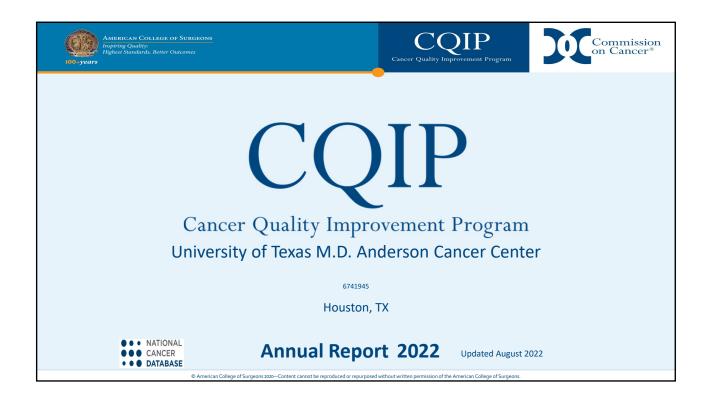
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Making Cancer History'

Utilizing Tumor Registry Data for Survival Analyses

- Diagnosis Date, Site, Histology, Stage
- Vital Status and Date of Last Contact/Death Date for life
- Overall Survival No restriction on cause of death
- Cancer Specific Survival Cause of death specific to cancer studying
- Challenging fields Recurrence, Disease Status, Cause of Death





Cancer Quality Improvement Program (CQIP)

- A data-driven, process and outcomes-based cancer quality improvement initiative
- Confidentially reports to 1,500 individual CoC-accredited hospitals their data as entered in NCDB (including comparisons with national data from all CoC-accredited programs)
- CQIP Slide Directory PDF located on the About CQIP tab provides information to support the reports, technical details, report creation, and scientific justification and references for quality measures
- 2022 release provides CoC-accredited facilities with data on:
 - Compliance with CoC-adopted quality measures
 - Volume data for complex surgical oncology operations with 30-day and 90-day mortality
 - Unadjusted and risk-adjusted survival data for selected cancer sites
 - Other clinical data and administrative data, which will be updated and expanded annually







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Final Thoughts on Leveraging Our Data

- Have confidence we are the expert with important data to share
- We know our data better than anyone else does, so collaborate
- Can combine data from many sources –TR data not always sufficient
- Providing data is not sufficient to guarantee authorship that is our job
- Must contribute more such as helping with the study concept, performing some data analysis, interpreting of the data and/or participating in the writing of the manuscript
- Ideas may originate from yourself or a researcher but you can improve their ideas
- If decide to publish in clinical journal always engage a clinician in that specialty



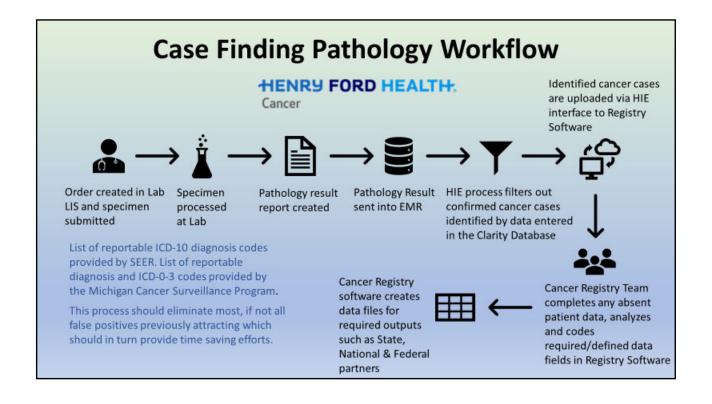
Final Thoughts on Leveraging Our Data

- Can often find a statistician/epidemiologist to do the analyses
- If not involved with any of the above be sure to ask them to acknowledge the registry that the data was retrieved from
- I use the following when I have only provided data For lectures or publications, please use the acknowledgment: "Patient population and various related data elements were identified and retrieved through a search of the Tumor Registry database maintained by the Department of Tumor Registry."

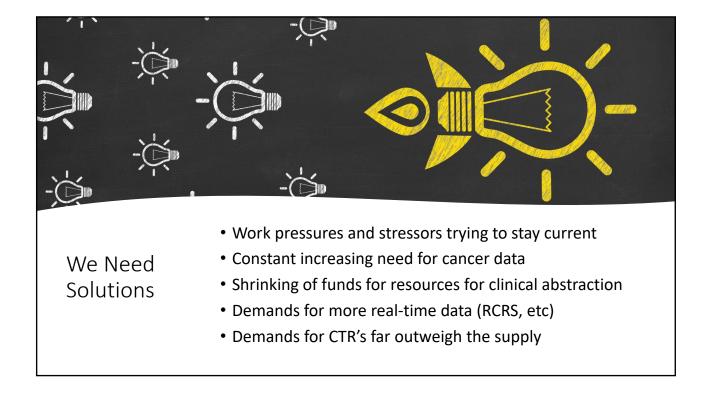


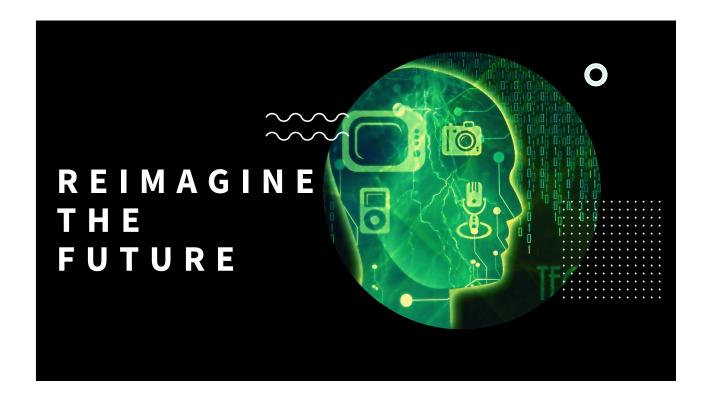
Thanks!!!!!

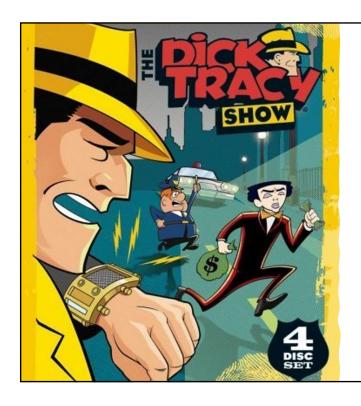






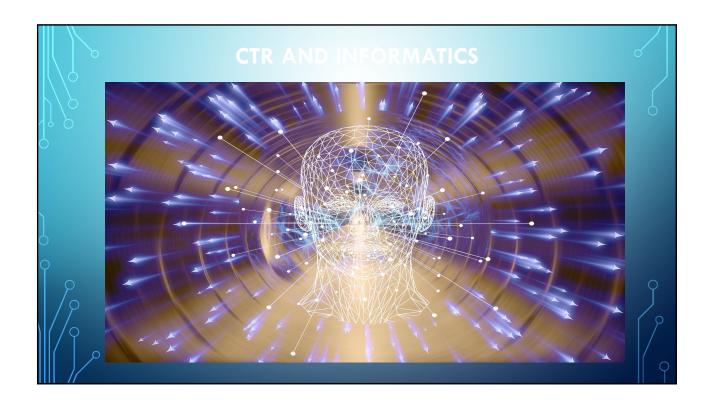




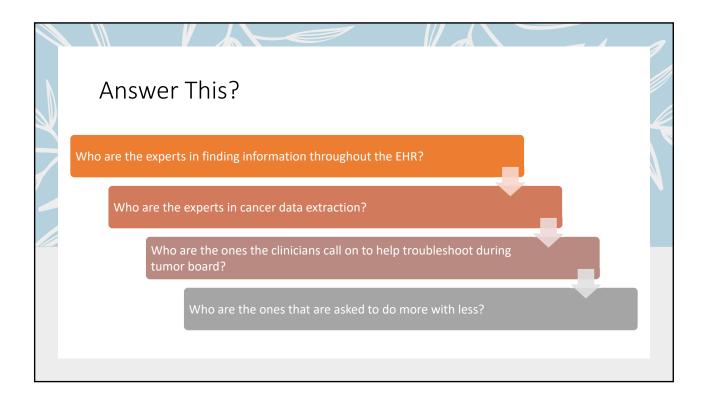


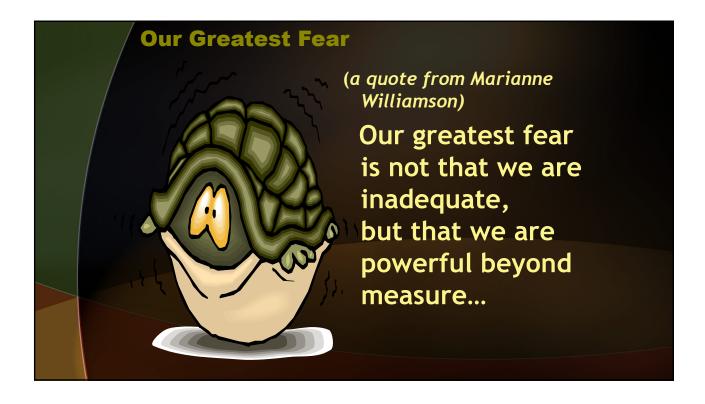
Who Remembers This?











CTRS ARE AWESOME!

- AJCC 8th edition dedicated to US
- CTRs in working sessions for protocol development
- CTRs working for software vendors
- CTRs working with internal IT team
- CTRs working for national and international data registries
- CTRs working for standard setters

TECHNOLOGY & INNOVATION APPLICATION TO THE nt, intuitive mechanism for the analysis of SEER*Prep- Converts ASCII text data files to the SEER*Stat database format, allowing you to analyze your cancer data using SEER*Stat.

SEER

urning Cancer Data into Discovery

- Health Disparities Calculator (HD*Calc)-An extension of SEER*Stat designed to generate multiple summary measures to evaluate and monitor health disparities. HD*Calc allows the user to import SEER data or other population-based health data and calculate any of eleven
- Methods & Tools for Population-based Cancer Statistics- Methods, software, and tools for the analysis, reporting, and visualization of cancer statistics. Includes geospatial methods and tools for state-level and small area cancer statistics.

SOURCE: https://seer.cancer.gov/registrars/tools-software.html

SEER REGISTRY SOFTWARE



• SEER Abstracting Tool (SEER*Abs) - Allows the strumor registrars to collect and store date abstracted from patients' medical records.

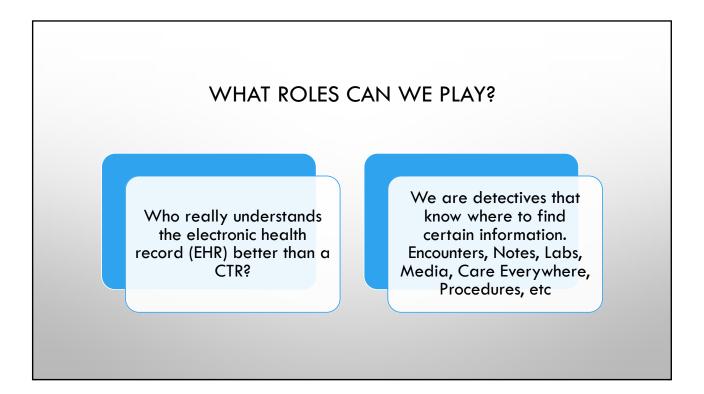
- SEER Application Programming Interface (API) Web service that provides access to various SEER Program data sets and algorithms. This service is available to developers who wish to incorporate SEER resources into their own systems.
- File*Pro View and manage data that are stored in text files. It is primarily designed for
 managing large cancer data files formatted according to the NAACCR Data Standards (Volume
 II), but it can be configured to be used with any data stored in a fixed column or CSV file format.
- Match*Pro Designed to find records that refer to the same entity across different data sources
 using a probabilistic record linkage framework based on the Fellegi and Sunter model.
- SEER Data Management System (SEER*DMS)- Provides support for all core cancer registry functions -- importing data, editing, linkage, consolidation, and reporting.

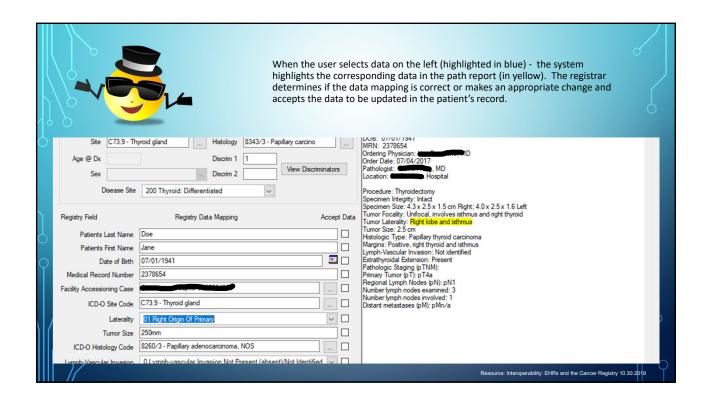
Impact of Informatics in the Registry

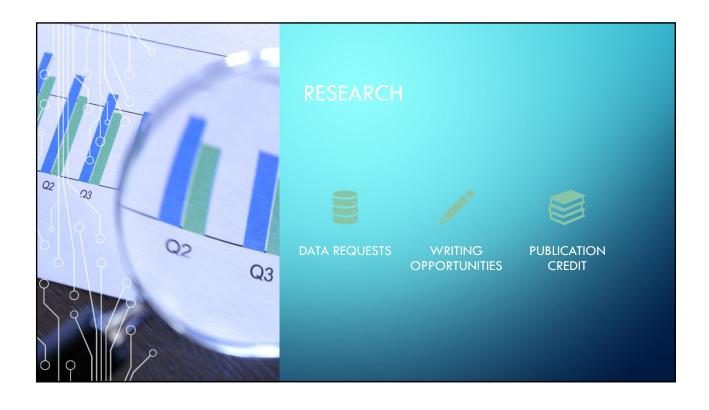
Improve registry operational processes through EHR automated workflows

Increase abstracting efficiency through partial abstraction

Support data-driven decision making for healthcare practitioners using dashboards











EDUCATION

FUN FAC!! NCRA has complimentary mini shorts from the Informatics committee that are on the CCRE webpage with more to come

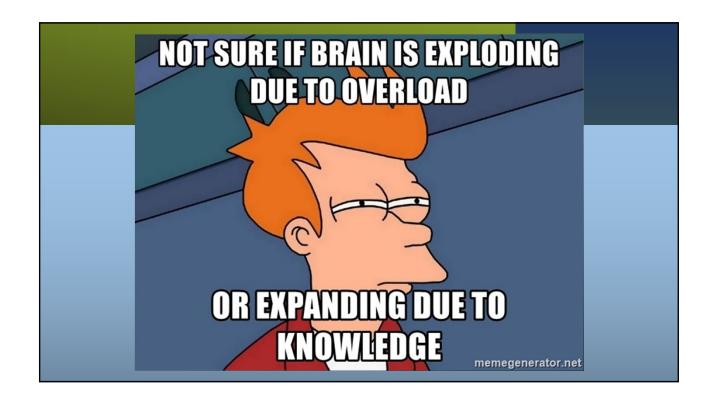
https://www.cancerregistryeducation.org/best-practices

- NCRA Knowledge based badge program in development for data management
- YouTube
- LinkedIn Learning
- NAACCR webinars
- State and National conferences
- NCRA Informatics

https://www.ncra-usa.org/Education/Informatics

• And so many more!













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CE Certificate Quiz/Survey

CE Phrase

Link

• https://survey.alchemer.com/s3/7032822/IT-Worked-for-Me-In-FUN-matics-in-the-Cancer-Registry

Coming UP...

Melanoma 2023

• Guest Host: Janine Smith
• 8/3/2023

Coding Pitfalls 2023

• Guest Host: Janet Vogel
• 9/7/2023

